

November 2015

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### **Recommended Citation**

John B. Oldershaw, Jeff Atkinson & Louis D. Boshes, *Persistent Vegetative State: Medical, Ethical, Religious, Economic and Legal Perspectives*, 1 DePaul J. Health Care L. 495 (1997)  
Available at: <https://via.library.depaul.edu/jhcl/vol1/iss3/3>

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# **PERSISTENT VEGETATIVE STATE: MEDICAL, ETHICAL, RELIGIOUS, ECONOMIC AND LEGAL PERSPECTIVES**

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## **INTRODUCTION**

Increasing attention has focused on the ethical, social, economical, and legal aspects of certain neurological conditions. These neurologic conditions include some that are refractory to known present day treatment. Due to the advancement of technology, it is possible to maintain patients for long periods of time on support systems, despite the fact those patients have no real hope of any cure or improved quality of life. However, the cost of such maintenance is very high in utilization of valuable resources. Nevertheless, arbitrary cessation of treatment is not morally or legally defensible.

Human beings are distinguished from other living beings by their souls, spirits, and personalities. These solely human aspects matter most to families and friends, and are the precise reason the decision making-process in conditions such as persistent vegetative state (PVS) is so difficult. When dealing with patients with PVS, physicians should

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advocate for the patient and protect the patient from further pain caused by unnecessary treatment. However, the physician should also be concerned with justice, and the appropriate allocation of resources and, in addition, with the possible legal ramifications.

From a historical perspective, the role of a physician has evolved from relatively passive to an active one. Scientific discoveries have enabled the physicians to have more control over physiologic and pathologic processes. From a societal viewpoint, the physician's stature has risen to a more paternalistic position where patients and their families often accept physician recommendations without question.

### PVS as a Paradigm

The problem of PVS is particularly vexing and lends itself as a model for other neurologic conditions. The term "vegetative state" was proposed by Jennett and Plum in 1972 to describe a chronic condition that encompasses diurnal wakefulness accompanied by a lack of cognitive function.<sup>4</sup> Eyes open spontaneously in response to verbal stimuli; but there are no localizing motor responses, and no response to verbal commands.<sup>5</sup>

Long-term survival in the vegetative condition occurs in a very small percentage of cases. Early diagnosis is difficult to make and is only evident as the convalescent days blend into weeks. After approximately one month the condition is, in most cases, fixed. However, there is one reasonably well documented report of a recovery after two years.<sup>6</sup> The patient was a forty-three year old man who remained vegetative for eighteen months after an anoxic, ischemic (lack of oxygenation) injury.<sup>7</sup> The patient neither opened his eyes nor had motor responses to noxious stimuli for six months.<sup>8</sup> He then awakened but remained vegetative for another year after which time he began to speak and follow commands.<sup>9</sup> After two years, he

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<sup>4</sup>See generally B. Jennett & G. Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 1 LANCET 734-747 (1972).

<sup>5</sup>*Id.*

<sup>6</sup>G.A. Rosenberg, S. F. Johnson, & R. P. Brenner, *Recovery of Cognition After Prolonged Vegetative State*, 2 ANN. NEUROL. 167-8 (1977).

<sup>7</sup>*Id.*

<sup>8</sup>*Id.*

<sup>9</sup>*Id.*

scored 100 on the verbal section of the Wechsler Adult Intelligence Scale (WAIS); but, even then, the patient was paralyzed in three extremities and totally dependent.<sup>10</sup>

In developing practical guidelines for withdrawal or termination of therapy, an algorithm can be helpful. Accurate diagnosis and prognosis is mandatory, and care must be taken to avoid bias. Thus, the algorithm must be applicable to all groups, regardless of economic or ethnic status. Religious, cultural, and ethical considerations are also critical in the decision-making process. If a person with PVS, in spite of being alive and recognizable to colleagues and relatives, is no longer present in the full human sense, then futility concepts must also be weighed. Economic costs and limited resources must be considered while avoiding legal vulnerability. This article examines these issues and suggests an approach toward resolution of the problem.

## MEDICAL PERSPECTIVE

### Defining PVS

PVS has been referred to by many other names including akinetic mutism, apallic syndrome and "locked in syndrome." However, none of these names squarely fit the clinical description. Obviously, not all patients are mute. Further, apallic syndrome refers to patients with apraxia and agnosia which involve right and left hemisphere cortical deficits, not necessarily hallmark conditions of PVS. "Locked in syndrome" is likewise inapplicable, because it refers to a deafferented or disconnected state with primary pathology situated in the ventral pons. However, PVS patients remain conscious but cannot communicate. Jennet and Plum borrowed from the Oxford English Dictionary the word "vegetate," which means "to live a physical life, devoid of intellectual activity or social intercourse;"<sup>11</sup> hence, the term persistent vegetative state.

Both the American Academy of Neurology and the American Medical Association define patients in a persistent vegetative state as being chronically awake, or suffering diurnal sleep-wake cycles, but without

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<sup>10</sup>*Id.*

<sup>11</sup>Jennett & Plum, *supra* note 1.

consciousness of their surroundings.<sup>12</sup> The primary pathology involves diffuse cortical dysfunction which may result from an acute incident such as trauma, ischemia, or hypoxia. Initially, and usually, this dysfunction renders the victim comatose prior to evolving into a true persistent vegetative state. PVS may also be caused by more chronic progressive illnesses such as Alzheimer's disease or demyelinating diseases. In PVS, the brain stem remains intact and accounts for the residual "vegetative" symptoms. PVS patients are able to open and move their eyes, have normal sleep/wake cycles, spontaneously smile, chew and swallow. Also, many PVS patients can maintain independent respiratory function; however, vocalization is often limited to grunting noises. Motor movement is restricted to posturing and reflexive withdrawal responses to noxious stimulation. Because the cerebral cortex is not functioning, PVS patients essentially have "amentia," a lack of language function. It is believed patients in a persistent vegetative state do not experience pain and suffering, because both emotions are conscious attributes requiring an intact cerebrum.

The diagnosis of PVS relies heavily on clinical assessment. Magnetic resonance (MR) and computerized axial tomography (CT) scans of the head show variable abnormalities, and electroencephalogram (EEG) is also unreliable. Depending on the etiology of the PVS, most patients are in a vegetative state for one month or more and do not recover to a level of independent function. The American Academy of Neurology recommends a waiting period of three months to establish the PVS diagnosis.<sup>13</sup> The American Medical Association recommends a twelve month waiting period to confirm the diagnosis and prognosis.<sup>14</sup>

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<sup>12</sup>*Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient: Adopted by the Executive Board, American Academy of Neurology, April 21, 1988, Cincinnati, Ohio, 39 NEUROLOGY 125-6 (1989) [hereinafter "American Academy of Neurology"]; Council on Scientific Affairs & Council on Ethical and Judicial Affairs, Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support, 263 JAMA 426-430 (1990) [hereinafter "AMA Councils"]*.

<sup>13</sup>American Academy of Neurology, *supra* note 12.

<sup>14</sup>AMA Councils, *supra* note 12.

### Distinguishing Brain Death From PVS

PVS is not brain death or coma. Brain death refers to complete failure of the functioning of the cerebral cortex and brain stem; and persistent coma involves extensive damage to the reticular-activating system, resulting in an inability to arouse the patient. With supportive care, many PVS patients survive for months, and even years.

The presently accepted standard definition of whole or global brain death, under the Uniform Determination of Death Act, specifies that an individual can be determined to be dead if the person has sustained irreversible cessation of all functions of the entire brain including the brain stem.<sup>15</sup> Redefining brain death to include patients in PVS and anencephalic infants poses clinical, legal, and moral dilemmas. A concept of cortical brain death involving the loss of higher brain function which then equates to the loss of personhood is not currently accepted as being equal to death.

In anencephalias, the infant is missing the higher brain centers and is termed by some as "brain absent." PVS patients, however, have lost what they once had, namely the part of the brain that mediates behavior constituting personhood, or functioning of that human behavior. Frequently, both anencephalias and PVS patients can breathe independently; and, therefore, neither qualify as having whole brain death or brainstem death. In anencephaly there is no possible future independent function; yet, despite periods of apnea, the brain stem is still intact. The patient usually continues to be totally dependent until such time that overwhelming infection intervenes.

A federal appeals court ruling determined a Virginia hospital must provide life support measures for an anencephalic infant.<sup>16</sup> Fairfax Hospital in Falls Church, Virginia was ordered to maintain an anencephalic infant in a decision based on the 1986 Emergency Medical Treatment and Active Labor Act (EMTALA), referred to as the Anti-Dumping Act.<sup>17</sup> This bill was designed to prohibit private hospitals from refusing uninsured patients

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<sup>15</sup>See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL BEHAVIORAL RESEARCH, *DEFINING DEATH: MEDICAL, LEGAL AND ETHICAL ISSUES IN THE DETERMINATION OF DEATH* (U.S. Gov't Printing Office, 1981).

<sup>16</sup>*In re Baby K.*, 16 F.3d 590, 592 (4th Cir. 1994).

<sup>17</sup>*Id.* at 598; 42 U.S.C. § 1395dd (1992).

needed emergency care.<sup>18</sup> The application of the anti-dumping law to the anencephalic infant was based on a finding that the infant suffered from the condition of apnea which requires emergency respiratory assistance.<sup>19</sup> The court avoided the issue of cortical brain death or absent cortex which would render further treatment futile.

A number of ethicists have suggested amending the Uniform Determination of Death Act to include a provision declaring anencephalic infants dead at birth in order to make their organs available for purposes of transplantation.<sup>20</sup> In contrast, there remains a vocal minority in philosophy, theology, and medicine who object to the concept of brain death, to say nothing of lack of personhood or other features of persistent vegetative state. That minority views the practice of organ transplantation as utilitarian, with a strong financial motivation for increasing the donor pool. This leads to the questioning of the intellectual foundations for defining "brain death".<sup>21</sup>

Rules and regulations regarding human tissue for transplantation have been proposed by the Department of Health and Human Services (HHS), and Food and Drug Administration (FDA).<sup>22</sup> Although the intent of this rule is to prevent the transmission of acquired immune deficiency syndrome (AIDS) and hepatitis through human tissue used in transplantation, the required donor testing and screening should also serve as a safeguard against premature decisions in the organ donation process.

### Accuracy of Diagnosis and Standard of Proof Required for PVS

The neurologic community generally concurs that PVS and coma are clinical diagnoses. The Plum and Posner definition of coma is a state of unarousable psychological unresponsiveness in which patients lie with their

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<sup>18</sup>*In re Baby K.*, 16 F.3d at 593.

<sup>19</sup>*Id.* at 596.

<sup>20</sup>G. J. Annas & S. Shimar, *Anencephalic Newborns as Organ Donors*, 259 JAMA 2284 (1988).

<sup>21</sup>R. Nilges, *Ethics of Brain Death, Thoughts of a Neurosurgeon Considering Retirement*, 47(2) PHAROS 34-35 (1984).

<sup>22</sup>See 21 C.F.R. § 16, 1270 (proposed Dec. 14, 1993).

eyes closed.<sup>23</sup> Jennett and Plum defined PVS as a state in which patients lack evidence of any adaptive response to the external environment, *i.e.*, the absence of any evidence of a functioning mind which is either receiving or projecting information in a patient who has long periods of wakefulness.<sup>24</sup> Therefore, the difference between coma and PVS is that coma is a closed-eye state of unresponsiveness, whereas PVS is an open-eyed condition with no evidence of conscious awareness.

A recent study found approximately 37 percent of patients after more than one month post injury were diagnosed with coma or PVS inaccurately.<sup>25</sup> The errors in diagnosis were believed to be the result of confusion in terminology, lack of extended observation of patients, and lack of skill or training in the assessment of neurologically devastated patients.<sup>26</sup>

In another study, the diagnosis of PVS in children was only 16 percent accurate in infants younger than two months, but 70 percent accurate in children who range in age from two months to two years.<sup>27</sup> Also, the diagnosis of PVS could be made in children with severe congenital brain malformations in 80 percent of cases.<sup>28</sup> Life expectancy from the time of injury for the various age groups with PVS was: 4.1 years for newborn to two months; 5.5 years for two months to two years; 7.3 years for two to seven years; and 7.4 years for those greater than seven years in age.<sup>29</sup>

Another recent study examining recovery from PVS involved a retrospective review of forty-three consecutive patients admitted to a unit specializing in the rehabilitation of people in the persistent vegetative

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<sup>23</sup>MEDICAL RESEARCH COUNCIL, BRAIN INJURIES COMMITTEE: A GLOSSARY OF PSYCHOLOGICAL TERMS COMMONLY USED IN CASES OF HEAD INJURY, MEDICAL RESEARCH COUNCIL WAR MEMORANDUM #4 HMSO (London, 1941).

<sup>24</sup>Jennett & Plum, *supra* note 1.

<sup>25</sup>N.L. Childs, et al., *Accuracy of Diagnosis of Persistent Vegetative State*, 43 NEUROLOGY 1465-67 (1993).

<sup>26</sup>*Id.*

<sup>27</sup>See generally, E.C. Meyer, et al., *The Persistent Vegetative State in Children. Report of the Child Neurology Society Ethics Committee*, 32 ANN. NEUROL. 570-76 (1992).

<sup>28</sup>*Id.*

<sup>29</sup>*Id.*



state.<sup>30</sup> It revealed 25 percent of these patients regained awareness four months or more after suffering brain damage.<sup>31</sup> Eye tracking was reported beginning between four months and three years, and response to command was reported beginning between four and twelve months.<sup>32</sup> While only one patient regained the ability to communicate, six were able to use nonverbal methods of indicating at least a "yes" or "no" response; and four were able to minimally speak.<sup>33</sup> Six patients remained totally dependent while two became independent in daily activities.<sup>34</sup> Four patients became independent in feeding, three required help, and four remained on gastrostomy feeding.<sup>35</sup> Thus, some patients can regain awareness after more than four months in a vegetative state and, although few reach full independence, most patients can achieve an improved quality of life within the limitations of their disabilities.<sup>36</sup> Nonetheless, the recovery period is prolonged and may continue for several years.<sup>37</sup>

Improvement in the accuracy of the diagnosis of PVS may be expected with some newer techniques. One of these is the cranial positron emission tomography (PET) scan.<sup>38</sup> This imaging technique detects production of cerebral glucose metabolism and may be used as a confirmatory test to the clinical diagnosis.<sup>39</sup> It has been used in both children and adults with a high degree of accuracy.<sup>40</sup> Other studies include planar brain scintigraphy oxygen seventeen uptake, and functional

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<sup>30</sup>K. Andrews, *Recovery of Patients After 4 Months or More in the Persistent Vegetative State*, 306 BRIT. MED. J. 1597-1600 (1993).

<sup>31</sup>*Id.*

<sup>32</sup>*Id.*

<sup>33</sup>*Id.*

<sup>34</sup>*Id.*

<sup>35</sup>*Id.*

<sup>36</sup>*Id.*

<sup>37</sup>*Id.*

<sup>38</sup>See generally D.E. Levy, et al., *Differences in Cerebral Blood Flow and Glucose Utilization in Vegetative Versus Locked-In Patients*, 22 ANN NEUROL 673-82 (1987).

<sup>39</sup>*Id.*

<sup>40</sup>*Id.*

magnetic resonance imaging (fMRI), all measuring changes in regional cerebral blood flow.<sup>41</sup>

A degree of diagnosis accuracy nearly 100 percent is necessary to make recommendations and terminal decisions in PVS. From a legal perspective, the diagnosis should be beyond a reasonable doubt, the highest level standard of proof, in order to obviate any potential allegation of culpable error. In addition, this standard should comport with the highest degree of medical and moral certainty.

## ETHICAL PERSPECTIVE

### Futility of Treatment v. Efficacious Treatment

For the purposes of this discussion, the aim of PVS treatment should be to return the individual to a sapient existence. However, this does not imply awakening to marginal consciousness without self awareness or capacity to interact humanly with one's family and friends. To return to permanent marginal consciousness without self awareness and intellectual capacity would be an unacceptable outcome of medical treatment, because the very essence of humanness would undoubtedly be lost. Unless there is reasonable hope of returning to a sapient existence, the individual is deemed "dying," even though the death may be prolonged by cure-oriented interventions such as dialysis, ventilators, or artificial nutrition and hydration. Quite simply, human beings are mortal; there is an inevitable necessity to die, because death is a normal part of the life process.

Medical futility can be distinguished in a quantitative and a qualitative sense. Quantitative futility refers to an expectation of success that is predictably unlikely, and qualitative futility refers to any treatment that merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care. Medical necessity, on the other hand, can be defined as services which have been reasonably well demonstrated to provide significant health benefit. Necessity is that care

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<sup>41</sup>See generally W. Oder, et al., *HM-PAO=SPECT in Persistent Vegetative State After Head Injury: Prognostic Indicator of the Likelihood of Recovery?*, 17 *INTENSIVE CARE MED.* 149-53 (1991).

which could be reasonably expected to return the patient to a sapient existence in more than 50 percent of cases.

The Hastings Center guidelines define "physiological futility" as treatment which is "clearly futile in achieving its physiological objective and so offers no physiological benefit to the patient."<sup>42</sup> Physiological here refers to reasonably normal function of the biological systems and includes sapient existence.<sup>43</sup> Once a decision is framed by the term "futility," it often provides justification for physicians to either override the wishes of the patient, family, or other surrogates, or make a nontreatment decision without obtaining informed consent or discussing the unilateral decision with the patient, family, or surrogate.<sup>44</sup> The latter, of course, does not consider the wishes, culture, religion or morals of the patient's family. For example, a judgment whether a short existence with severe disability is a life worth living is a personal value judgment, and not merely a medical judgment. A person could effect closure of his temporal life during this time and, thus, financial and business matters could sufficiently be settled. Further, family and personal closure could be affected and spiritual preparations made. Another aspect of futility is the consideration of limited health care resources that could be available for other patients with a more reasonable expectation of success.<sup>45</sup>

Medical futility is a psychologically tolerable way of speaking about the most difficult end of life decisions within families and communities. It provides a framework within which the value of life, the inevitability of death, professional responsibility, and social justice can be reconciled.

### **Futility of Treatment versus Futility of Life**

In PVS, a determination could be made that the PVS life is a life not worth living. Unfortunately, this phrase has negative connotations, because it was used more than sixty years ago by the Nazis as an attempt to

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<sup>42</sup>R. Cranford & L. Gostin, *Futility: A Concept in Search of a Definition*, 20 LAW, MED. & HEALTH CARE 307 (1992).

<sup>43</sup>*Id.*

<sup>44</sup>*Id.*

<sup>45</sup>*Id.*

rationalize the elimination of persons whose lives were viewed as "defective."

The concept of futility may be quite variable and have different meanings to different people depending on whose "quality of life" is in question. For example, a smile may be a satisfactory level of recovery for a mother helping her son in a PVS after a motorcycle accident. However, life in a wheelchair may not be satisfactory to an athlete who was vigorous and physically active prior to the accident. Therefore, quality of life and futility depends greatly on the patient's individual outlook on life and the outlook of a patient's family.

Professional medical associations and organizations may develop practice guidelines to define futility, but decisions about futility require the nature and value of life to be defined. Physicians, however, cannot extend their expertise to determining these values except at extreme limits. In one case, it may be too early to determine whether the condition of PVS is permanent or transient, as in the first weeks after the onset of PVS. In another case, there may be clear, objective, clinical, and scientific evidence of permanent PVS.

Except at these extremes, physicians cannot substitute their own judgment for that of either the patient's family or the court. However, it would be impractical for the court to decide every futility case. The ponderous and costly nature of such cases would negate any economic benefit resulting from the termination of life-sustaining treatment.

A distinction must be made between futility of treatment and futility of life. A decision not to use medically futile therapy does not devalue life. Also there is no legal or moral obligation to render futile treatment. The question may be raised whether an existing or proposed treatment offers reasonable hope of benefit to the patient. Here, one must understand the patient's concept of benefit. To some patients, longer survival in an atmosphere of intensive care, compared with a shorter life span at home, may not be considered "a benefit." On the other hand, more aggressive therapy for a terminal, but conscious patient, may be desirable to achieve maximum time to conclude personal or business affairs.

Certain treatments may not be futile in themselves. However, in the overall scheme, such treatments would be burdensome to the family by maintaining a life that has little or no expectation of return to a sapient

existence. A distinction may be drawn between offensive and defensive futility analysis.<sup>46</sup> In defensive futility analysis, a family may have reached a judgment based on medical, religious, social, and personal grounds that a particular form of life support should no longer be employed.<sup>47</sup> Futility is then employed as a defense against charges that the withdrawal of treatment amounts to abuse of the patient or homicide.<sup>48</sup> This defense could only be overcome if the treatment was shown to benefit the patient, or if an element of criminal intent motivated the decision to withdraw treatment.<sup>49</sup> By contrast, the concept of offensive futility analysis involves health care providers in discussions about the withdrawal of treatment or involves the initiation of legal action to this end.<sup>50</sup> Courts with jurisdiction over personal guardianship may be called upon to assess futility criteria in those cases involving incompetent patients.

It is important to avoid any perception or suggestion of a double standard implying the patient knows best so long as the patient or surrogate wishes to forego treatment, but the doctor knows best if otherwise. Moreover, an overly paternalistic view of physician autonomy may result in disregard for the patient's or family's wishes.

In determining the burdens or benefits of a particular treatment, it is appropriate for physicians to consider that the mechanics of intensive care themselves contribute to a poor quality of life. However, a conclusion that the mental or physical life of the patient is of poor quality, and not worth the effort to sustain it, is a more questionable type of futility analysis by the physician.

Further, futility analysis cannot assess a family's experience of closeness to a patient who, in the medical view, may appear beyond the capacity for such an experience. The family may perceive the patient is in some contact, because patients occasionally show response to family and loved ones but not others. This phenomena may have a scientific basis verifiable with metabolic imaging in the future. Also, futility analysis

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<sup>46</sup>See generally E.R. Grant, *Medical Futility: Legal and Ethical Aspects*, 20 LAW, MED. & HEALTH CARE 330-35 (1992).

<sup>47</sup>*Id.*

<sup>48</sup>*Id.*

<sup>49</sup>*Id.*

<sup>50</sup>*Id.*

cannot measure how much time is enough for a family to grieve and accept the inevitable.

The success of futility analysis depends upon both a recognition of its limitations as a form of moral certainty, and also on a recognition of its value as a means of moral persuasion. To this end, ethics committees have an important and practical educational role. These committees can provide an opportunity for a balanced discussion of patient rights to terminate care based on individual autonomy and the patient's right to health care.

### **Removal of Cardiopulmonary Support, Antibiotic Therapy and Other Medical Treatments**

In most instances, the families of patients with PVS are in agreement with physicians in terms of withholding measures such as antibiotics, cardiopulmonary resuscitation, and dialysis. Only ardent pro-life advocates disagree with this position. However, cardiorespiratory arrest seldom occurs, and repeated infections are resolved in nearly 50 percent of cases even without the use of antibiotics.

### **Withdrawal of Artificial Nutrition and Hydration**

One aspect of the debate over stopping treatment in PVS concerns suffering the patient may experience with removal of a respirator, or the discomfort associated with starvation and dehydration after removal of a feeding tube. PVS destroys the capacity to perceive a wide range of stimuli and the neocortical or higher brain functions needed to generate a self-perceived, affective response such stimuli. Pain cannot be experienced by a brain that no longer retains the neurological substrate for suffering.

A growing body of literature indicates the symptoms of death by starvation are not severe. Following cessation of fluid intake, hypernatremia (excess salt condition) develops slowly and induces confusion, weakness, and lethargy which eventually progresses to impaired consciousness. The patient slowly progresses into unconsciousness over a period of days without complaining of pain or discomfort. In otherwise alert cancer patients, final hours of life are often marked by a sense of well-

being following cessation of fluid therapy.<sup>51</sup> One recurring physical complaint related to the absence of oral fluid intake is a dry mouth.<sup>52</sup> This minimal discomfort can be alleviated by attending to oral hygiene such as providing ice chips, moistening cloths, and mildly irrigating. Total starvation is ironically associated with euphoria, in contrast to semi-starvation which produces intense discomfort and depression. Rather than of inducing pain, food deprivation typically causes hypalgesia and/or analgesia.

An important feature of this dying process is the attentiveness of the medical personnel, family members, and friends of the patient. A sense of abandonment is common in the awake patient, causing psychological suffering which often exceeds any purely physical pain or discomfort.<sup>53</sup>

### RELIGIOUS PERSPECTIVE

Culture influences the way in which patients, families, health care providers, and members of institutional ethics committees understand and resolve ethical difficulties. Included in culture are the shared ideas, beliefs, and meanings that human groups consider important in their lives. Culture develops around affinities such as national heritage, occupation, political persuasion, religion, or neighborhood. Further, the attributes of social class, age, and sex also contribute to varying cultural frameworks.

Culture affects our notions of what practices are clinically right or wrong and, therefore, gives meaning to the experience of illness and suffering defining what life and death are. Culture delineates the nature of ourselves, our desires, our relations with others, and what we consider to be appropriate and ethical in the context of health care. Culture leads us to choose a physician instead of a shaman for the relief of pain. It is culture that allows some of us to expect a terminal diagnosis to be withheld from a patient, a fetus to be granted the status and privileges of a person, or no technological effort to be spared in the prolongation of a patient's

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<sup>51</sup>G.F. Cahill, *Hyperglycemic Hyperosmolar Coma: A Syndrome Almost Unique to the Elderly*, 31 J. AM. GERIATRIC. SOC'Y 103-5 (1983).

<sup>52</sup>M.J. Baines, *Control of Other Symptoms*, in THE MANAGEMENT OF TERMINAL ILLNESS (C.M. Saunders ed., 1978).

<sup>53</sup>Timothy Quill, *Doctor, I Want to Die. Will You Help Me?*, 270 JAMA 870-73 (1993).

life. One's agreement or disagreement with those expectations is most likely a product of one's own culture.

One example of this cultural influence is the Christian concept of the meaning of dying as put forth by several Jesuit theologians.<sup>54</sup> In this theological view, the spirituality of a Christian dying is the manifestation of fundamental faith.<sup>55</sup> In the Eucharist, the principal focal point of Christian faith, members of the faith relive, over and over again, their union with Christ's life, death, and resurrection.<sup>56</sup> It is believed that as the person receives and responds to living a life in Christ's likeness, the person is eventually drawn to receive and enter into the grace of sharing and dying of Christ.<sup>57</sup> In this fashion, Catholic moral theology rejects clinging to biological existence at all costs because not only the living, but also the dying, are objects of freedom of faith.<sup>58</sup> Acceptance of dying is an integral feature of this belief.<sup>59</sup>

On the other hand, measures that precipitate death or shorten the process of dying are generally rejected due to societal notions against suicide and homicide. However, measures to relieve pain and suffering are considered to be morally justified even though death may be hastened as a result. This is the principle of the double effect. The intent in "double effect" is not to cause death by deliberate overdose of medication, but to use sufficient analgesic to alleviate the suffering of the patient. The rejection of treatment that prolongs dying is strongly encouraged. In fact, Catholic moral theology mandates a duty to reject burdensome medical treatment and proclaims individuals must take responsibility for the manner of their dying.<sup>60</sup> The contemporary hospice movement, which provides for support and alleviation of pain in the dying process, is an important part of this concept. Here, a Christian's dying is looked upon as the final gift of God's calling to be conformed to Christ.

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<sup>54</sup>See generally James F. Bresnahan, *Catholic Spirituality and Medical Interventions in Dying*, 164 AMERICA 670-75 (1991).

<sup>55</sup>*Id.*

<sup>56</sup>*Id.*

<sup>57</sup>*Id.*

<sup>58</sup>*Id.*

<sup>59</sup>Bresnahan, *supra* note 54, at 670-75.

<sup>60</sup>*Id.*



The exercise of freedom in dying as proposed by Karl Rahner, a German Jesuit theologian, and Teilhard de Chardin, a French Jesuit philosopher, emphasize autonomy for those near death.<sup>61</sup> Dying patients must permit themselves to be loved and cared for by dear ones and care givers.<sup>62</sup> On the other hand, the first concern of dying is usually for those who will be left behind.<sup>63</sup>

The Christian approach, according to these Jesuit theologians, is that prayerful reflection on Christ's dying should, shape decision making about one's own death. In turn, this should influence decisions regarding advanced directives in the form of a living will or durable power of attorney for health care. Second, one's spirituality, or one's day-to-day practice of his Christian faith should shape the individual and the common response to others in their suffering and dying. Prayerful acceptance of dying will allow one to deal appropriately with the dying of others and prevent prolonging the dying process or resorting to premature induced death. The tendency of modern high technology medicine is to maintain life-sustaining treatments rather than shift to care which primarily aims to relieve suffering and enable the terminal patient to interact freely with loved ones and friends. Thus, guidelines are essential to limit medical interventions that merely prolong dying.

Other religions, in particular Middle and Far Eastern beliefs, also include a concept of survival in the afterlife by the spirit or soul of the individual. In Islam, Allah is God, and Mohammed is the prophet that shows the way to Allah. This faith is significantly based on the continuation of the spirit or soul into an afterlife. The single deity in Buddhism and multiple deities in Hinduism also are representative of afterlife goals. Although the Jewish faith does not emphasize an afterlife, there is concern with a singular deity and following the prescribed life rules in the Talmud.

The concepts of an afterlife have also been described in the works of the ancient Egyptians, Greeks and Romans especially in the writings of Homer, and Virgil. The concepts of an afterlife with reward and

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<sup>61</sup>TEILHARD DE CHARDIN, ON LOVE AND HAPPINESS (1984).

<sup>62</sup>*Id.*

<sup>63</sup>*Id.*

punishment for behavior in this life can be found in these and other works. An example is the crossing of the river Styx, with the boat man, Charon, ferrying the souls over to the netherworld.

### **Religious Views on End of Life Issues**

Judaism forbids the hastening of death but allows removing impediments to death.<sup>64</sup> Reformed and some orthodox rabbis permit the disconnection of intravenous apparatus as an impediment. Jewish families usually request that life sustaining measures be continued for a varying period of time after which a final decision may be made.

Islam believes that illness is a result of God's or Allah's trial of the people. Physical illness may be cured by recitation of the Koran or prayers. Under Islamic belief, Allah is the creator of life, and no individual "owns" his or her life. Therefore, no person can actively terminate such life.

Lutherans accept medical judgment on the best course of action. They focus on the reality of the situation while affirming the resurrection of the body in immortality after death. Pentecostal religions invoke the New Testament gifts of healing. Believers turn to healing through prayer and maintain a belief in miracles. Therefore, Pentecostal believers generally will not terminate the PVS.

Afro-Caribbean religions, including some religious groups involving Haitians, Cubans, Jamaicans, Puerto Ricans and African Americans, consider healing as the work of religion. All healing takes place through ritual adjustments between the person who is ill and his or her relationships with the living, the dead, and the divine. In these religions, physicians play a lesser role in healing and decision-making.

Indigenous groups in Mexico believe in traditional curing practices performed by a healer, or "Curandero." The primitive common concept of illness is fright, which jars the soul loose from the body. This loss of the soul is considered the real cause of the illness, and therefore, the Curandero begs the soul to return. However, after folk attempts to restore

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<sup>64</sup>A.K. Gordon, Remarks at Chicago Neurological Society Spring Symposium on PVS (May 19, 1993) (text available from the Chicago Medical Society).

health fail, Christian missionaries may be sought to supplement such methods.

The traditional Irish view reveals that life is full of suffering and it must be accepted with stoic resignation. If the person is to recover, then he shall independent of any efforts that are made.

From a religious view, many systems consider death a transition to another life and, thus, death does not necessarily mean the termination of existence. Therefore, decisions regarding sustaining life in the face of hopelessness or futility may not be quite so final or awesome, particularly if appropriate counseling is obtained by a religious figure, whether it is a priest, rabbi, or a minister of the respective faith of the dying person.

When dealing with religious and ethnic issues, it is important to resolve conflicting beliefs through knowledge and sensitivity. Also, breaching the language barrier with interpreters and involving ministers or clerics of the respective religions will assist in dealing with ethnically diverse patients and their families. It is best, of course, that individuals be attended to by these ministers seen on a regular basis prior to the illness.

### ECONOMIC PERSPECTIVE

Health care economics involves balancing costs and benefits of alternative therapies. In recent years, economics of high technology medicine has become an important issue, particularly for neurology and neurosurgery specialists. Health care rationing appears inevitable; in fact, clandestine rationing of health care has existed for a quite some time, *e.g.*, "slow codes" and benign neglect. Even Hippocrates listed a number of disorders, such as severe head injuries that were not to be treated.

There are many principles of ethics involved in this decision making process, including equity in the distribution of health care resources, beneficence, non-maleficence and patient autonomy.

Cost benefit analysis and cost effectiveness are means by which the best use of resources is achieved. Cost effectiveness deals with efficiency of health care delivery systems and is monitored by utilization review departments. Performance indicators are systematically and continuously reviewed by health care facilities and third party payors such as private

insurance companies, Medicare, and Medicaid. Cost benefit analysis is more difficult and involves ethical as well as medical value judgments.

The cost of maintaining life must be balanced against the human values of palliation, or the alleviation of suffering. If the only goal of medical treatment was to return a patient to an economically contributing role in society, all terminal conditions would go untreated whether the survival time is days, weeks, or months.

Quality of life is an important feature here, however, it is not a clearly defined subject. What does quality of life mean? A good quality of life for one who has significant disabilities may be considered a poor quality of life by another whose body image cannot tolerate lesser deficits. This disparity is exemplified by the cases of Edward Hyde and Stephen Hawking, both of whom developed amyotrophic lateral sclerosis or Lou Gehrig's disease. This condition causes a progressive loss in motor strength with eventual total dependence on others. In the early stages of the disease, and while only mildly affected, Mr. Hyde was unable to tolerate the inevitable and inexorable course of the illness. Therefore, he became one of the early assisted suicides of Dr. Kevorkian.

Professor Hawking on the other hand, although severely disabled, continues to carry on his brilliant work in theoretical physics at the University of Cambridge, U.K., where he occupies the Newton Chair. Dr. Hawking has shown no inclination toward suicide, assisted or otherwise.

One method of assessing cost benefit is to measure outcomes with and without treatment. However, this is still largely anecdotal, and accurate outcome data for most conditions is often not applicable in individual cases. The reason is there are multiple patient factors; and the treatments themselves are not static, but rather evolving.

In order to estimate costs of various technologies and treatments it is necessary to maintain detailed and extensive records. With the use of computer systems, it soon will be possible to estimate, with considerable accuracy, the costs of alternative therapies initially, as well as days, weeks, and even months after treatment.

It is more difficult to assess benefits in terms of alleviation of anxiety and reduction of symptoms. Treatment without cure may nonetheless result in reduced dependency and resumption of former life activities. An example of this is the radiation of certain spinal cord tumors, which may

produce a temporary remission of symptoms, but provide no permanent cure. Even this outcome must be evaluated, with and without high technology therapy, in order to arrive at a true cost benefit assessment.

Another thing to consider is that frequently, severe untreated conditions will not terminate quickly. It is very difficult to determine duration of life in terminal conditions with any degree of certainty, except when vital functions begin to fail. Even then, predictions are surprisingly inaccurate and thus, the cost of dying with no treatment may also be significant.

One study indicated cost cutting measures utilized at the end of life have been less effective than originally expected. Using figures from 1988, even if all cost cutting measures, such as no high tech, no futile intervention, and only care according to advanced directives, were used for every American who is terminally ill, the savings in the 2.17 million deaths that year would have been 3.3 percent of the nation's total health spending of \$500 billion. However, that figure would be lessened for the following reasons:

- (1) many elderly people are afraid to sign right-to-die documents that delegate legal power over their health care;
- (2) surrogates and families are often less willing to terminate health care than the patients themselves;
- (3) many people who are not going to accumulate large bills because their medical care does not depend on cardiopulmonary resuscitation or expensive technology or respiratory support machinery;
- (4) even though complex medical intervention is not used, other necessary kinds of care such as effective pain relief, nursing, and help in daily living are quite expensive; and
- (5) hospital stays may be reduced, but the use of nursing homes, home health care, and hospices will increase.

In many cases, it is often unclear whether aggressive treatment will be futile, or truly life saving, until it is attempted. Since there is no reliable means to identify patients who will die, it is impossible to accurately say which patients will benefit from intensive interventions and which ones will

not. Such indeterminacy is present even when an assessment is made a few days before death.

For advanced directives, the average hospital bill for those without an advanced directive was \$56,300 as compared to \$61,589 for those with a living will, and \$58,346 for those with a durable power of attorney. For do-not-resuscitate (DNR) orders, the cost of care for those with DNR orders was \$62,594 for 616 patients, compared with \$57,334 for 219 patients without DNR orders.

Clearly, resource conservation is important; and triage for the use of life sustaining interventions is reasonable and necessary. However, it appears the proffered substantial cost savings by limiting life sustaining interventions and limiting aggressive care at the end of life is illusory.

Several scientific and economic studies have examined and analyzed the persistent vegetative state. In one study, children were studied over a five year period.<sup>65</sup> Most of the patients were stable after the first year of home care; and care takers felt most children had minimal awareness, that is, voice recognition.<sup>66</sup> However, every child remained totally dependent, and the cost of the care per patient averaged \$90,000 per year.<sup>67</sup> In the long term, the prognosis for children discharged from the hospital in a PVS was very poor; in fact, 40 percent died during these five years.<sup>68</sup>

In another study, twenty-three patients in PVS were reviewed, all requiring at least one type of mechanical assistance such as respirators, nasogastric or gastrostomy tubes, or intravenous lines.<sup>69</sup> Each case was complicated by incontinence and, in a majority of cases, by decubitus ulcers, pneumonia, and urinary tract infections.<sup>70</sup> The bills for thirteen patients averaged \$170,000, and the length of stay for all patients averaged almost two-hundred days with the total number of "bed days" averaging twelve and a half bed years.<sup>71</sup>

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<sup>65</sup>Al. Fields et al., *Outcomes of Children in a Persistent Vegetative State*, 21 CRIT. CARE MED. 1890-94 (1993).

<sup>66</sup>*Id.*

<sup>67</sup>*Id.*

<sup>68</sup>*Id.*

<sup>69</sup>D.M. Kaufman & R.B. Lipton, *The Persistent Vegetative State--An Analysis of Clinical Correlates and Costs*, 92 N.Y. ST. J. MED. 381-84 (1992).

<sup>70</sup>*Id.*

<sup>71</sup>*Id.*

Survival of patients in PVS may extend for many years depending heavily upon the level of supportive care. A Hastings Center report in 1988 estimated the annual cost for PVS patients as high as \$1 billion.<sup>72</sup> Thus, from a cost effective standpoint, poor outcomes do not seem to justify requirements for mechanical support. The consideration of resource utilization and resource availability is significant, because other individuals whose outcome is more optimistic may be denied beneficial therapies due to resource limitations.

Although insurance companies have sought to limit reimbursement for unproven, and seemingly futile measures, those with sufficient funds have been successful in extracting payments through legal action.<sup>73</sup> This capricious policy seems unfair because the process favors the rich over the poor and the assertive and articulate over the reticent and less expressive.

## LEGAL PERSPECTIVE

### Role of Ethics Committees

An Institutional Ethics Committee (IEC) is a multi-disciplinary body commissioned by a health care institution for the consideration and application of societal and ethical values to aspects of patient care, or other select institutional issues associated with the delivery or non-delivery of health care services.

Ethics committees on ethical consultations have been present in an unofficial or quasi-official capacity for many years, particularly in church-run institutions associated with religious bodies. One of the earliest stimulus for the initiation of an institutional ethics committee was the development of the kidney dialysis machine in the early 1960's, used for treatment of end-stage renal disease.<sup>74</sup> This procedure necessitated selection and rejection of patients, since resources were extremely limited.

In recent years, there has been rapid growth of medical technologies

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<sup>72</sup>R.E. Cranford, *The Persistent Vegetative State: The Medical Reality*, 18 HASTINGS CENTER REP. 31 (1988) (Special Supplement).

<sup>73</sup>See Gina Kolata, *Patients' Lawyers Lead Insurers to Pay for Unproven Treatments*, N.Y. TIMES, Mar. 28, 1994, at A1.

<sup>74</sup>G. J. Annas, *Ethics Committees: From Ethical Comfort to Ethical Cover*, 21 HASTINGS CENTER REP. 18 (May/June 1991).

resulting in a medical ability to sustain physiological or vegetative existence almost indefinitely. However, there remain finite health care resources, and patient care selection must be made. Additionally, there is a lack of clarity and uniformity in the law regarding termination of life-sustaining therapies. The advanced directive legislation of recent years has been fostered by the work of ethics committees. Finally, there has been a perception of a need for health care institutions to have a single, multi-disciplinary body or forum to address complex mixes of medical, ethical, and legal issues.

Presently, neither federal, nor Illinois law, requires the formation of institutional ethics committees or IECs. Also, the Joint Commission on Accreditation of Health Care Organizations (JCAHO) has no formal ethics committee requirement in their guidelines. However, some legal factors leading to the voluntary formation of IEC's have included:

- (1) The President's Commission for the Study of Ethical Problems in Medicine and BioMedical and Behavioral Research Commission;<sup>75</sup>
- (2) "Baby Doe I" federal regulations;<sup>76</sup>
- (3) "Baby Doe II" federal regulations;<sup>77</sup>
- (4) State enactment of advanced directive statutes such as the Illinois Living Will Act,<sup>78</sup> and the Powers of Attorney for Health Care Act,<sup>79</sup> and
- (5) State enactment of health care surrogate acts such as the Illinois Health Care Surrogate Act.<sup>80</sup>

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<sup>75</sup>PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL AND BEHAVIORAL RESEARCH COMMISSION, DECIDING TO FORGO LIFE SUSTAINING TREATMENT: ETHICAL, MEDICAL AND LEGAL ISSUES IN TREATMENT DECISIONS (Mar. 21, 1983).

<sup>76</sup>Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794 (1994); 45 C.F.R. § 84 (1996).

<sup>77</sup>45 C.F.R. § 1340 (1996) (Child Abuse Amendments of 1984 and 1986 effective Oct. 9, 1985).

<sup>78</sup>755 ILCS 35/1-10 (West 1996) (effective Jan. 1, 1984).

<sup>79</sup>755 ILCS 45/4-1 - 4-12 (West 1996) (effective Sept. 22, 1987). All fifty States now have some form of advanced directive statutes.

<sup>80</sup>755 ILCS 40/1-55 (West 1996) (effective Sept. 26, 1991).



Other factors include:

- (1) The Federal Patient Self-Determination Act of 1990;<sup>81</sup>
- (2) Patient Rights Standards of the Joint Commission on Accreditation of Health Care Organizations (JCAHO);<sup>82</sup> and
- (3) Report No. 34 of the AMA Council on Ethical and Judicial Affairs on decisions to forego life sustaining treatment for incompetent patients.<sup>83</sup>

The Ethics Committee is a forum for identification, exploration, and consultation on bio-medical, ethical, and related legal issues affecting hospitals, patients, and staff. Committee functions include: assisting administration and health care staff in the development and review of policies and guidelines on ethical concerns, responsibilities and performance; providing consultation to the hospital staff, patients and family members on ethical, moral, and philosophical issues related to patient care; and, coordinating and providing education on ethical issues in health care.

There is no mandatory decisional power, but the conclusions and recommendations of the committee have considerable influence on clinical services.

### **Procedures for Ethics Committees**

The IEC generally meets on a regular basis to consider policy recommendations and to provide consultations for ethical dilemmas that occur during the course of patient care. A structured procedure for consultation is followed; and, after review of the patient's background, including cultural and religious factors, the matter at issue is presented to the Ethics Committee. In making recommendations, the Committee follows the state as well as the Federal Law.

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<sup>81</sup>42 U.S.C. § 1396a(w) (1994).

<sup>82</sup>JOINT COMMISSION ON ACCREDITATION OF HEALTH CARE ORGANIZATIONS, ACCREDITATION MANUAL FOR HOSPITALS, 105-6 (1993).

<sup>83</sup>Reports of the Council on Ethical and Judicial Affairs of the AMA, Vol. II, No. 2, July 1991.

Elective cases are reviewed at the regularly scheduled ethics meeting. In emergencies, a quorum of committee members, either in person or by conference call, renders a decision. Retrospective reviews of cases may be carried out to provide more information on patient care as well as to gather data for policy formation.

### **Records**

Many issues that come under the purview of the ethics committee have legal implications; and, therefore, it is necessary to maintain accurate and detailed documentation of discussions and recommendations. This ordinarily takes the form of the "minutes" of the committee meeting itself.

### **Immunity**

There is statutory immunity for IEC members under state law. For example, in Illinois, relevant statutes include the Living Will Act,<sup>84</sup> the Power of Attorney for Health Care Act,<sup>85</sup> and the Health Care Surrogate Act.<sup>86</sup>

### **Education**

The educational function is carried out by committee member participation in various bioethical conferences and dialogues at the local, state, and national level. In addition, education of the hospital medical staff is performed at set intervals to review the requirements and any changes in advance directive statutes or surrogate decision making laws.

Ethics committees must acknowledge both patients' rights and providers' moral duties in their deliberations. With increasing patient and family participation, paternalistic attitudes from caregivers are no longer appropriate and may denote bias. In other words, overbearing attitudes may be construed as indicative of a personal interest in a particular outcome.

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<sup>84</sup>755 ILCS 35/7 (West 1996).

<sup>85</sup>755 ILCS 45/4-8 (West 1996).

<sup>86</sup>755 ILCS 40/35 (West 1996).

### Right to Die Issues and Cases

When suffering from PVS, the patient loses any semblance of functional and quality living. The purpose of allowing a patient to die is to preserve that patient's dignity. *Roe v. Wade*<sup>87</sup> and other abortion rights decisions have produced an interpretation of the Fourteenth Amendment to the United States Constitution that assures a right to personal autonomy over one's body and existence. Earlier court decisions such as *Karen Ann Quinlan*<sup>88</sup> in 1976 and *Nancy Cruzan*<sup>89</sup> in 1990 established the right of the hopelessly ill to refuse life preserving medical treatment and to allow a dignified, natural death.

The *Karen Ann Quinlan* case<sup>90</sup> was the first to focus national attention on the problems created by the use of medical maintenance systems. These problems entailed the prolongation of patient suffering, the potential for family financial ruin, and the misutilization of scarce medical resources. *Karen Quinlan* overdosed with Phenobarbital and Librium.<sup>91</sup> After it became apparent she would not regain consciousness, *Quinlan's* father requested artificial life support be withdrawn.<sup>92</sup> *Quinlan's* physicians refused, fearing a potential charge of homicide.<sup>93</sup> *Quinlan's* father was unable to order a withdrawal of treatment himself, because *Quinlan* was twenty-one years old. Therefore, because *Quinlan* had reached the age of majority, her father was no longer her natural guardian. *Quinlan's* father was then appointed her legal guardian treating subsequently ordering the withdrawal of treatment.<sup>94</sup> However, the treating physicians refused to comply with this request; and, as a result, the matter was taken to court.<sup>95</sup> The New Jersey Supreme Court held *Quinlan's* father, acting as *Quinlan's* legal guardian, could order the withdrawal of treatment.<sup>96</sup> Further, such

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<sup>87</sup>*Roe v. Wade*, 401 U.S. 113, 93 S. Ct. 705 (1973).

<sup>88</sup>*In re Quinlan*, 355 A.2d 647 (N.J. 1976).

<sup>89</sup>*Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 110 S. Ct. 2841 (1990).

<sup>90</sup>*In re Quinlan*, 355 A.2d 647 (N.J. 1976).

<sup>91</sup>*In re Quinlan*, 348 A.2d 801, 806 (N.J. Super. Ct. Ch. Div. 1975) *modified and remanded* 355 A.2d 647 (N.J. 1976).

<sup>92</sup>*In re Quinlan*, 355 A.2d at 651.

<sup>93</sup>*Id.* at 651-52, 669-70.

<sup>94</sup>355 A.2d 647, 653 (N.J. 1976).

<sup>95</sup>*Id.*

<sup>96</sup>*Id.* at 671-72.

withdrawal of treatment would not be considered homicide, but rather the recognition of the exercise of a legitimate right to refuse treatment in Quinlan's best interest.<sup>97</sup> Quinlan was then weaned from the ventilator; surprisingly, continued to breathe spontaneously for an additional nine years while maintained on artificial feedings. She eventually succumbed to overwhelming infection and died.

Eleven years after Quinlan's death, a similar situation arose in the case *In re Jobes*.<sup>98</sup> Mary Ellen Jobes was pregnant when she was involved in a car accident and subsequently required surgical intervention for removal of her fetus.<sup>99</sup> During the surgery, Jobes suffered an ischemic episode (lack of oxygen or blood flow in the brain or both) and failed to awaken.<sup>100</sup> For several years, Jobes' life was maintained by tube feeding.<sup>101</sup> However, when Jobes' husband wanted to discontinue all treatment, her physician and nursing home refused.<sup>102</sup> On August 10, 1987, the Supreme Court of New Jersey ruled in favor of the family on the basis of substituted judgment involving the surrogate making a treatment decision based on the patient's preference.<sup>103</sup> Treatment was then terminated.

Paul Brophy was also in PVS after undergoing an unsuccessful operation for a ruptured basilar tip aneurysm.<sup>104</sup> His life was maintained by artificial feeding for three years<sup>105</sup> despite numerous witnesses who attested to Brophy's premorbid wish and intention not to live a vegetative existence.<sup>106</sup> The treating physician and trial court, nonetheless, refused the request of Brophy's wife to discontinue tubal feeding.<sup>107</sup> A Massachusetts court determined the preservation of life, the prevention of suicide, and the ethical precepts of the medical profession were state interests sufficient to

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<sup>97</sup>*Id.* at 669-70.

<sup>98</sup>*In re Jobes*, 510 A.2d 133 (N.J. Super. Ct. Ch. Div. 1986).

<sup>99</sup>*Id.* at 134.

<sup>100</sup>*Id.*

<sup>101</sup>*Id.*

<sup>102</sup>*Id.* at 135.

<sup>103</sup>*In re Jobes*, 510 A.2d 133, 135-36 (N.J. Super. Ct. Ch. Div. 1986).

<sup>104</sup>*Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626, 628 (Mass. 1986).

<sup>105</sup>*Id.*

<sup>106</sup>*Id.* at 632 n.22.

<sup>107</sup>*Id.* at 632.

require continued tubal feeding.<sup>108</sup> However, the Supreme Court of Massachusetts allowed discontinuance of further treatment,<sup>109</sup> and Brophy died eight days later.

Nancy Cruzan entered a PVS after sustaining severe injuries in an automobile accident.<sup>110</sup> Without court approval, hospital employees refused to honor the request of Cruzan's parents to terminate artificial nutrition and hydration.<sup>111</sup> A Missouri court authorized the termination, finding evidence of Cruzan's desire not to live in a PVS from the testimony of Cruzan's former housemate.<sup>112</sup> Cruzan had allegedly stated she would not wish to continue her life if sick or injured unless she had the potential to return to a halfway normally existence.<sup>113</sup>

The Missouri Supreme Court reversed.<sup>114</sup> While recognizing a right to refuse treatment embodied in the common law doctrine of informed consent, the court questioned its applicability in this case.<sup>115</sup> The court also declined to read a broad right to privacy that would support an unrestricted right to refuse treatment within the state constitution.<sup>116</sup> The court then decided the Missouri living will statute evidenced a state policy strongly favoring the preservation of life.<sup>117</sup> Cruzan's statements to her housemate were seen as unreliable and insufficient for determining Cruzan's intent.<sup>118</sup> The court rejected an argument claiming Cruzan's parents were entitled to order the termination of her medical treatment concluding no person may assume such a choice for an incompetent individual in the absence of the living will statute requirements or other "clear and convincing evidence" of the patient's wishes.<sup>119</sup>

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<sup>108</sup>*Id.* at 634.

<sup>109</sup>*Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626, 639-40 (Mass. 1986).

<sup>110</sup>*Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 266 (1990).

<sup>111</sup>*Id.* at 267-68.

<sup>112</sup>*Id.* at 268.

<sup>113</sup>*Id.*

<sup>114</sup>*Id.*

<sup>115</sup>*Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 268-69 (1990).

<sup>116</sup>*Id.* at 268.

<sup>117</sup>*Id.*

<sup>118</sup>*Id.*

<sup>119</sup>*Id.* at 268-69.

The United States Supreme Court held in *Cruzan* that when addressing the withdrawal of life saving treatment, the Constitution did not forbid Missouri to require clear and convincing evidence of an incompetent person's wishes.<sup>120</sup> Most state courts have based a right to refuse treatment on the common-law right to informed consent and a constitutional right to privacy.<sup>121</sup> A competent person arguably has a liberty interest in refusing unwanted treatment under the Due Process Clause of the Constitution, however, this right must be balanced against relevant state interests.<sup>122</sup> While the Court only assumed the premise that a competent person has a constitutionally protected right to refuse life saving hydration and nutrition,<sup>123</sup> it held that an incompetent person does not necessarily possess the same right; because that person is unable to make an informed and voluntary choice.<sup>124</sup>

Missouri has established a procedural safeguard to assure the action of surrogate decision makers conforms to the wishes expressed by the patient while competent.<sup>125</sup> As a result, the State can effectively guard against potential abuses by surrogates who may not act in the patient's best interest.<sup>126</sup> The State may also properly decline to make judgments about the "quality" of an individual life and need only assert a general, unqualified interest in the preservation of human life to weigh against the constitutionally protected interests of the individual.<sup>127</sup>

The Court felt it was self-evident that these interests are more substantial, on an individual and societal level, than those involved in common civil disputes.<sup>128</sup> The clear and convincing evidence standard also served as a societal commentary about how the risk of error should be distributed between the litigants.<sup>129</sup> Missouri permissibly places the increased risk of an erroneous decision on those seeking to terminate life-

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<sup>120</sup>*Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 280 (1990).

<sup>121</sup>*Id.* at 271.

<sup>122</sup>*Id.* at 278-79.

<sup>123</sup>*Id.* at 279.

<sup>124</sup>*Id.* at 280.

<sup>125</sup>*Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 280 (1990).

<sup>126</sup>*Id.* at 281.

<sup>127</sup>*Id.* at 282.

<sup>128</sup>*Id.* at 283.

<sup>129</sup>*Id.*

sustaining treatment.<sup>130</sup> An erroneous decision not to terminate results in a maintaining of the status quo, allowing room for a potentially wrong decision to be corrected, or its impact mitigated by an advancement in medical science or the patient's unexpected death.<sup>131</sup> However, an erroneous decision to withdraw such treatment is not capable of correction.<sup>132</sup>

The Missouri Supreme Court did not commit constitutional error in concluding the evidence introduced at trial did not amount to clear and convincing proof of Cruzan's desire to withdraw hydration and nutrition.<sup>133</sup> The trial court had not adopted a clear and convincing evidence standard and Cruzan's statement claiming she did not want to live life as a "vegetable" did not specifically deal with the withdrawal of medical treatment or hydration and nutrition.<sup>134</sup>

Nancy Cruzan's parents were undoubtedly qualified to exercise a right of "substituted judgment" if such judgment was mandated by the Constitution.<sup>135</sup> However, for the same reasons it may require clear and convincing evidence of a patient's wishes, Missouri may also choose to defer solely to those wishes rather than confide in the decisions of close family members.<sup>136</sup>

Although the five-four majority supported the individual's constitutional right to refuse medical treatment, the opinion was based on the liberty and Due Process guarantees of the Fourteenth Amendment and the common law doctrine of informed consent. In its decision, the Court did not make a distinction between the withdrawal of nutrition and hydration versus the removal of cardio-respiratory support. This decision, however, supported the validation of living wills and durable powers of attorney for health care.

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<sup>130</sup>Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 283 (1990).

<sup>131</sup>*Id.*

<sup>132</sup>*Id.*

<sup>133</sup>*Id.* at 285.

<sup>134</sup>*Id.*

<sup>135</sup>Cruzan v. Director, Missouri Dep't of Health, 497 U.S. 261, 286 (1990).

<sup>136</sup>*Id.* at 286-87.

The Missouri courts did eventually find clear and convincing evidence of Cruzan's desire to die, and artificial nutrition and hydration were subsequently removed. Nancy Cruzan died ten days later.

These cases illustrate the varied approaches utilized by courts when resolving PVS issues. There is emphasis on patient autonomy and thus, if the patient, or her surrogate acting on her behalf, has made a competent, informed decision to discontinue treatment in light of uncontrollable suffering, futile treatment, or poor quality of life, the decision must be honored.

### Illinois Law

Two different forms of advanced directives are available to patients in Illinois: the Power of Attorney for Health Care (PAHC) and the Living Will. The PAHC enables patients to choose an agent, ideally a close relative or friend familiar with the values of the patient, to make all health care decisions in the event the patient becomes mentally incapacitated.<sup>137</sup> The PAHC has flexibility since it enables the agent chosen by the patient to make decisions for a temporarily incapacitated patient and for an incompetent patient who becomes terminally ill.<sup>138</sup> A physician complying in good faith with the wishes of the patient's agent will have legal immunity for medical decisions including the decision to discontinue life sustaining treatment.<sup>139</sup>

In Illinois, a living will is much more restrictive. It enables a competent patient to instruct an attending physician to withdraw death-delaying interventions if the patient becomes incompetent, terminally ill, or is imminently threatened with death.<sup>140</sup>

Advanced directives are intended to enhance the autonomy of patients, assuring their values are given primary consideration in medical decisions after the patient becomes incompetent.<sup>141</sup> In order to achieve this end, competent patients should be encouraged to discuss with their chosen agent and physician, their values and preferences, such as what quality of

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<sup>137</sup>See 755 ILCS 45/4-1 - 4-12. (West 1996).

<sup>138</sup>755 ILCS 45/4-1 (West 1996).

<sup>139</sup>755 ILCS 45/4-8 (West 1996).

<sup>140</sup>See 755 ILCS 35/1 - 10 (West 1996).

<sup>141</sup>755 ILCS 35/1 (West 1996).



life restrictions would be unacceptable. Indeed, decisions made by a patient's agent should reflect the values of the patient.

The Illinois Health Care Surrogate Act (HCSA) helps to assure a patient's wish to forego life sustaining treatment will be followed even if the patient does not have an advanced directive.<sup>142</sup> The HCSA provides physicians and surrogates of qualified patients with the power to withdraw or withhold life-sustaining treatment, and thereby allow the patient to die naturally without turning to the expensive and time consuming legal process.<sup>143</sup> Qualifying patients are those who have one of the following: a terminal condition; permanent unconsciousness; or an incurable and irreversible condition that imposes severe pain or an otherwise inhumane burden on the patient which may ultimately lead to death.<sup>144</sup> By following the guidelines set forth in HCSA, health care providers gain immunity from criminal prosecution and civil suit regarding decisions to forego life support -- with the exception of gross and flagrant negligence.<sup>145</sup>

This mandate has been implemented at most hospitals by providing standardized forms to be read and signed by the patient at the time of admission. However, hospital admissions officers should be trained to counsel and advise the patient and answer any questions about the material.

### Representative Law in Other States

Virtually all states have enacted natural death or death with dignity statutes; however, most states do not specifically address PVS. In 1977, California was the first state to enact its own Natural Death Act, aimed at granting a competent adult the legal right to make a written directive to withhold or withdraw life sustaining procedures in the event of terminal illness.<sup>146</sup> Other states have enacted similar provisions providing their citizens with the opportunity for death with dignity by means of a living

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<sup>142</sup>See 755 ILCS 40/5 - 55 (West 1996).

<sup>143</sup>*Id.*

<sup>144</sup>755 ILCS 40/10 (West 1996).

<sup>145</sup>755 ILCS 40/35 (West 1996).

<sup>146</sup>Note, *The California Natural Death Act: An Empirical Study of Physicians' Practice*, 31 STAN. L. REV. 913 (1979).

will. Enacted in 1982, Delaware's Death with Dignity Act<sup>147</sup> was the first act to provide a durable power-of-attorney for health care statute.

Another approach to PVS is a rationing program which has been implemented in several other states including Oregon. Under the Oregon Health Plan, there is a standard benefit package for Medicaid patients that will not pay for the treatment of certain conditions such as severe brain injury and aggressive medical treatment for end-stage cancers.<sup>148</sup> PVS is not specifically mentioned in the broad outline, but it is listed in the category of "severe brain injury" where treatment is considered ineffective or futile. However, comfort care such as pain management and hospice care is provided for these conditions.

### Federal Law

In December 1991, the Patient Self Determination Act (PSDA) took effect, thereby requiring all patients admitted to a hospital or nursing home receive written information notifying them of their right to make decisions concerning medical care. Such rights include the right to accept or refuse medical treatment and to formulate advanced directives consistent with the laws of their state. At the time of admission, all patients must be asked whether they have already executed an advanced directive. However, the provision of care may not be conditioned or influenced by whether an advanced directive is in place.<sup>149</sup>

Under the PSDA, hospitals must develop policies assuring that a patient's advanced directive is implemented to the greatest extent permissible under state law.<sup>150</sup> Health care providers who object to an advanced directive on the basis of conscience may transfer the patient to another provider who agrees to abide by the terms of the advanced directive.

Patients are not required to fill out advanced directives while hospitalized, nor are they required at the time of admission to decide whether they wish to receive various life-sustaining interventions if

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<sup>147</sup>DEL. CODE ANN. tit. 16, §§ 2501-2509 (1983).

<sup>148</sup>M.J. Garland, *Justice, Politics and Community: Expanding Access and Rationing Health Services in Oregon*, 20 LAW, MED. & HEALTH CARE 67-81 (1992).

<sup>149</sup>42 U.S.C. § 1396(a)(w)(1)(C) (1994).

<sup>150</sup>42 U.S.C. § 1396a(w) (1994).

necessary. Yet, with a formal policy, eliciting patients' wishes regarding death and dying will become a routine part of the admission process. The formalization of the process helps remove the pessimistic implication of imminent death from later discussions.

### **Representative Law in Other Countries**

In the health care systems of Canada, Germany, Sweden, New Zealand, and Australia, the problems associated with maintaining PVS patients are not specifically addressed.<sup>151</sup> This might be explained by considering that the high technology commonly utilized in the United States is not as readily available in other countries.

In the Netherlands, assisted suicide is an option in hopeless or terminal conditions, however, the process must be voluntary and formal confirmation by a colleague must be obtained. The United Kingdom and Norway also condone assisted suicide in the same manner.<sup>152</sup>

### **CONCLUSIONS & RECOMMENDATIONS**

The condition of PVS remains somewhat fluid, and the accuracy of this important diagnosis is currently limited. While futility of treatment may be determined, futility of life is dependent on other factors including religious and cultural issues. Ethics committees play an important role in weighing the issues of medicine, economics, and law in these cases.

Economics and resources are important considerations in the care and treatment of PVS patients. However, the anticipated cost savings associated with the limitation of high technology treatments or support may not materialize in these cases, because other costly measures must be incorporated to provide supportive and palliative care.

Advance directive statutes exist in varying forms in all fifty states. Nevertheless, most PVS patients do not execute advanced directives.

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<sup>151</sup>Colleen M. Grogan, *Deciding on Access and Levels of Care: A Comparison of Canada, Britain, Germany, and the United States*, 17 J. HEALTH POL., POL'Y & L. 213-32 (1992).

<sup>152</sup>J. Van Eys, Remarks: Dying Well: A Major Conference (May 25, 1994) (text available in The Ethics Center at Garrett-Evangelical Seminary/Northwestern University, Evanston, IL).

When pressed with the withdrawal and removal of nutrition and hydration, physicians must be sensitive to the symbolic value of feeding and providing nutrition, as well as the appearance of abandonment when treatment is removed. Other supportive care must be continued regardless of the prognosis. Patients and surrogates must be informed in advance that withholding medical nutrition and hydration may be more comfortable than providing some food and water.

Many critics are rightfully concerned that abuses may occur and, therefore, safeguards must be incorporated into any adopted policies or enacted legislation. Care must be taken so the permissibility of withholding medical nutrition and hydration will not be transformed into a policy to forego treatment with vulnerable populations such as the elderly and mentally impaired. Likewise, cost containment pressures must not lead physicians to become social gate keepers at the bedside. This questionable role would inevitably be viewed as bias by some and may even lead to legal vulnerability. Quite simply, decisions must be shared by all parties concerned.

Finally, in applying any algorithm, health care providers, especially physicians, must thoroughly communicate with patients and surrogate decision makers in order to avoid potentially drastic misunderstandings.

## APPENDIX

The criteria of brain death, as established by the ad hoc committee of the Harvard Medical School<sup>153</sup> are the following:

- (1) Unreceptivity and unresponsivity - total unawareness to externally applied stimuli and complete unresponsiveness.
- (2) No movements or breathing - No spontaneous muscular movement or spontaneous respiration or response to stimuli such as pain, touch, sound or light. Observation should cover a period of at least one hour by a physician.

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<sup>153</sup>H.K. Beecher, Chair, *A Definition of Irreversible Coma: Report of the ad hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 JAMA 337-340 (1968).

- (3) No reflexes - A) Fixed dilated pupils, non-reactive to direct source of light; B) No ocular movement; C) Absent corneal and pharyngeal reflexes; D) Absent deep tendon reflexes.
  - (4) Flat EEG- \*The EEG should be run at maximum gain. \*\*There should be no response to noise or pain. \*\*The EEG should be repeated at least once within twenty-four hours later with no change.
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- (1) In addition, condition of hypothermia must be excluded, that is, temperature below 90 degrees Fahrenheit or 32.2 degrees Centigrade and,
  - (2) Central nervous system depressant such as barbiturates should not be present. The EEG is a confirmatory finding for cerebral death but is not a sufficient criteria itself. In Illinois and Indiana there are slight variations to the previously listed protocol. The following clinical criteria for brain death are necessary and sufficient to diagnose brain death: the patient must be in deep coma - unresponsive to verbal or painful stimuli; no brain stem reflexes (spinal reflexes may be present); no spontaneous respirations; no spontaneous movements or posturing; the cause of coma must be established and sufficient to account for the loss of brain function; criteria for brain death are not valid where the level of central nervous system depressants is greater than therapeutic levels. When clinically indicated a drug screen must be performed to exclude this possibility; criteria for brain death are not valid if the patient's temperature is below 32.2 degrees Centigrade (90 degrees F); the criteria must be met at the time of a repeat evaluation two hours apart. If gross irreparable brain trauma is present, this interval may be reduced; there is a difference in the evaluation of children in that in children under two months it is recommended that two examinations and EEG's be performed at least forty-eight hours apart. In patients two months to one year, two examinations and EEG's separated by at least twenty-four hours should be done. A repeat examination and EEG are not necessary if a concomitant cerebral radio nuclide angiographic study demonstrates no visualization of cerebral arteries.

Another test commonly used is called the apnea test. Because the respiratory drive is the most caudal of the brain stem responses, an apnea study should be considered if performed in a specific manner. If spontaneous respiration is not stimulated after the arterial PCO<sub>2</sub> is 60mm/Hg or greater, then the presence of brain stem death is confirmed. This definition is also consistent with global or whole brain death or brain stem death.

## **PROPOSED ALGORITHM**

### **Guidelines for Termination of Treatment for PVS Patients**

#### **Phase 1: Assessment**

A. Functional assessment performed, after following criteria are:

1. brain death criteria have NOT been met<sup>a</sup>;
2. vital signs are normal (exception, if on ventilator respiration rate need not be normal)<sup>b</sup>;
3. key blood work value has normalized times<sup>c</sup>;
4. toxic screen negative<sup>d</sup>;
5. anticonvulsant levels have non-toxic times.<sup>e</sup>

Assessment should include specific mention of level of interaction with surroundings:

1. response to verbal, written or gestural communication;
2. presence, extent and type of eye contact;
3. autonomic response to interpersonal interaction;
4. specific mention of the presence or absence and type of voluntary movements.

Specific documentation of quantitative neurophysiological function, including some or all of the following:

1. EEG times<sup>f</sup>;
2. evoked potentials;
3. SPECT/PET brain scans;
4. pharmacological challenge with central nervous system stimulant;
5. second opinion.

If unable to adequately assess status, re-attempt in one month.

If the assessment corroborated severe impairment such that the prior human qualities of the patient are no longer evident and there are no known effective therapies to redress this condition, then the following procedure will be initiated.

## **Phase 2: Procedure**

- A. Formal notification by attending physician in writing of a management meeting concerning the patient will be made to family, friends and/or significant others including close friends if appropriate, attending physician (or his/her physician representative), hospital counsel (or his/her representative), and appropriate clergy.
- B. Formal meeting with family, friends, and/or significant others with attending physician, hospital counsel, and appropriate clergy.  
Specific topics discussed include:
  - 1. Telling the family of the severity of condition and the prognosis;
  - 2. Review of advance directives to include: living will, power of attorney for health care, written or oral statements by patient, etc.;
  - 3. Social/psychological impact of continued care ;
  - 4. Utilization of resources such as critical care beds and technologies which are costly and limited in availability;
  - 5. Impact of decisions on possible future litigation on the patient's or hospital's behalf;
  - 6. Discussion of options:
    - a. Continued prolongation of life with no restriction;
    - b. DNR only, with continuance of all standard medical care;
    - c. DNR plus other options listed below:
      - i. passive neglect - no further or new diagnostic testing or treatments;
      - ii. active withdrawal - withdrawal of hydration and nutrition<sup>2</sup>;
  - 7. Recommendation for termination of care;
  - 8. Right to transfer to other hospital, long term care facility or hospice;



9. Names of appropriate consultants for an independent second opinion if desired;
10. Reasonable time frame for patients and family or surrogate to consider the options.

### C. Plan

1. If a consensus plan is established, it will become part of the medical record and be signed by the attending physician (or his designate), and hospital counsel to insure that proper procedure is followed;
2. If a consensus plan cannot be reached, Hospital/Medical Center Ethics Committee will meet expeditiously and render a written opinion and recommendation with regard to the appropriate level of therapy for the patient. This may be used as evidence in a legal hearing. The hearsay objection may be overcome if the person who drafted the report is available to testify. The Ethics Committee may choose to utilize the Neuroscience Subcommittee of the Hospital Ethics Committee for this purpose;
3. If a consensus plan still cannot be established then alternative dispute resolution (ADR) will be instituted involving all parties with a reasonable medical legal and personal interest in the patient, *i.e.*, hospital, ethics committee, hospital counsel, attending physician, family members, family attorney, clergy. This will include negotiation, mediation, arbitration, etc.

Alternative dispute resolution consists of extrajudicial methods of resolving controversies without court involvement. It is not a new system and has actually been in existence since ancient times when early tribal chiefs or "wise old men" performed such functions as mediation and arbitration. In recent years, ADR has been incorporated into the court system where at certain stages in the court proceedings, the parties may either voluntarily or by compulsion enter into mediation, arbitration, conferences, mini-trials, or similar procedures.

The principal ADR processes are:

1. mediation/negotiation;
2. arbitration; and
3. summary jury trial.

Mediation is an informal nonbinding and voluntary procedure. The third party is neutral and selected by the two parties. There is unrestricted presentation of evidence, arguments, and interests. The outcome is a mutually acceptable agreement or no agreement, and the process is private.

Arbitration is a more formal procedure, is binding, and it is mandatory if contractual. Similar to mediation, the third party or parties are neutral and selected or appointed by the parties concerned. There is presentation of proof and arguments. The outcome is a principled award. While arbitration is private, it is subject to judicial enforcement.

The summary jury trial, mini-trial, and judicial settlement conferences are considered pre-trial screening panels. The purpose of a pretrial screening panel is to determine the merit of a claim prior to a civil court action. This process encourages a solution based on the objective opinion of the panel and may be deemed admissible in court.

4. As a last resort, a court decision is requested. In the guidelines on futile care at Santa Monica Hospital Center in California,<sup>154</sup> a cost shifting mechanism is introduced at this point. When it is determined that the patient can no longer benefit from the hospital stay, but the patient or his family insists on him remaining there, a mechanism for personal payment is initiated where the family assumes the cost.

- D. The attending physician will again review the signs, symptoms, and history of the patient and confirm that there is certainty of diagnosis

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<sup>154</sup>HOSP. & HEALTH NETWORKS, Feb. 20, 1994, at 28.

and prognosis to implement this algorithm. (The standard is a high degree of medical certainty or beyond a reasonable doubt). This will serve as a final confirmation of the clinical status. It should be done immediately prior to implementing the options in 2(B)(6) above.

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Notes:

- a. Termination of life support in the face of brain death has already been established. The difficult issue involves patients with residual neurological function, but with severe impaired high cortical function.
- b. This implies that the patient's medical condition is not in flux, and therefore, it is a reasonable time to make a binding functional assessment.
- c. *See supra* b.
- d. This is a safeguard against making a patient evaluation in the context of the unintentional or intentional presence of poisonous, illicit, or otherwise harmful substances acting upon the patient.
- e. Many brain injury patients are on anticonvulsant medications in order to suppress harmful seizure activity. Very high or toxic levels can suppress higher cortical functions thereby falsely impairing intrinsic residual function. Repeat tests to insure accuracy.
- f. Clear and convincing standard of evidence. Because of its uncertainty in these cases, one or two abnormal EEG exams would fall into the preponderance level of evidence only.
- g. This is considered to be a swift and compassionate means to terminate life.